Sainsbury K, Walburn J, Vieira R, Sniehotta FF, Weinman J, Sarkany R, Araujo-Soares V. Using n-of-1 methodology to inform the development of individualized, evidence-based interventions for patients with xeroderma pigmentosum. *In: International Congress of Behavioural Medicine*. 2016, Melbourne, Australia: Springer.

USING N-OF-1 METHODOLOGY TO INFORM THE DEVELOPMENT OF INDIVIDUALISED, EVIDENCE-BASED INTERVENTIONS FOR PATIENTS WITH XERODERMA PIGMENTOSUM

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Introduction: XP is a very rare inherited disease affecting 1 in 250,000 people (~90 UK patients). It involves extreme sensitivity to UV light; the only treatment is complete avoidance of UV – not going outside during daylight, fitting UV screens to windows, or ensuring complete skin coverage. Most patients die by age 35, usually from skin cancers. No research on the psychological consequences of XP or factors relating to UV protection currently exists.

Methods: In phase one, an N-of-1 study was conducted in 25 adult XP patients, as part of a mixed methods approach to intervention development. Participants wore a UV wristwatch and completed a brief survey, including adherence behaviours and psychological predictors (e.g., emotions, self-regulation), for 50 consecutive days. Constructs were selected from the theory domains framework and a review of behavioural maintenance theories.

Results: N-of-1 analysis revealed differences in the patterns of predictors of adherence across participants, supporting the need for an individualised approach. Following MRC guidelines, phase two involves the development of a series of individualised interventions to improve adherence, informed directly by the specific predictors identified for each participant in phase one (e.g., including BCTs to target motivation, planning, or emotions). After PPI feedback and piloting, the interventions will be tested in a waitlist-controlled RCT in a matched sample of non-adherent adults.

Conclusions: The XP study provides a novel example of systematic intervention development in a rare and unstudied condition, which could be used as a model for understanding and improving health outcomes in other rare diseases.

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Word count: 250